Suggested Guidelines for Developing an Epidemiologic Profile for HIV Prevention Community Planning

Introduction

General Comments

These guidelines have been developed to assist persons in compiling and interpreting epidemiologic data for a statewide, regional, county, or metropolitan profile of HIV/AIDS. Using these guidelines is an optional part of the community planning process.

The epidemiologic profile should provide a thorough understanding of the HIV epidemic among the various populations in a planning region and should identify characteristics of both HIV-infected and HIV-negative persons at high risk in defined geographic areas who need prevention services. The profile should provide a list of such populations in the community as a starting point for consideration by the planning group.

The profile should be compiled, interpreted, and summarized by epidemiologists in the state or local health department in collaboration with interested planning group members. Planning group members should, at a minimum, assist in framing the questions to be addressed by the profile and in identifying population groups who may require special consideration.

In developing an epidemiologic profile, four key questions should be answered:

1. **What are the sociodemographic characteristics of the population?**
2. **What is the impact of HIV/AIDS on the population?**
3. **Who is at risk for becoming infected with HIV?**
4. **What is the geographic distribution of HIV infection?**

Question 1 seeks information on important characteristics of the population of the planning region and provides the setting for understanding the HIV epidemic. Question 2 asks for general information to describe the extent of the HIV epidemic in the planning region. Question 3 asks for the most crucial information for understanding which population groups are at high risk for becoming infected with HIV. Most of the

data that are widely available to answer Question 3 describe those currently infected with HIV with the assumption that those who have become infected, particularly persons most recently infected, are characteristic of those in the community most likely to become infected in the near future. Question 4 seeks information to describe the geographic distribution of HIV-infected persons in the planning region.

These guidelines suggest tables, graphs, and maps of data that may be used to answer each question or, if answers are not attainable, to at least address each question. Some of the examples provided are drawn from profiles submitted to CDC as part of HIV prevention applications. Others represent tabulations done by CDC using nationally available data. In addition, examples of epidemiologic profiles from Florida that were developed as a "pilot" of these guidelines are shown in Appendix B. All examples have been approved by local or state health departments or are from published reports or publicly available information. The examples are only for illustrating the guidelines and are not intended for any other use.

The guidelines, which draw on several information systems that are readily available to all or most states, should be used in conjunction with Chapter 4, "Developing an Epidemiologic Profile," in the *Handbook for HIV Prevention Community Planning* (Appendix C), which describes data sources and their strengths and limitations. These guidelines focus on the data sources described in Chapter 4 that are the most valuable for developing an epidemiologic profile. The proposed tabulations should be considered as a starting point; many planning regions that have access to additional data sources may go into further detail. Conversely, some areas will not have the information resources to complete all of these tables, graphs, and maps (e.g., the clinic-based HIV seroprevalence surveys are conducted in a limited number of sentinel cities). While those areas with more information will be able to develop a more detailed profile of the HIV epidemic, "more data" is not a prerequisite to developing an epidemiologic profile that will be useful to community planning groups. A desire to collect more information should not detract from efforts to make the best use of information that is locally available.

Although the tables, graphs, and maps used to address the key questions should be available to all members of the planning group, epidemiologists familiar with the local data should first interpret, synthesize, and summarize the data in a manner that enhances their relevance for community planning group members and that uses appropriate presentation methods (e.g., narrative, graphic, or tabular). Presentation to the planning group may be organized by the key questions, drawing together perspectives from different sources of data.

Instructions for Using This Document

This document is organized in sections based on the four key questions. Although each section can serve as an independent module, answering all four questions will provide a

comprehensive profile. Check-off boxes throughout the document signify recommended analyses for the epidemiologic profile. The boxes are found under each subsection and are listed in Appendix A. Some boxes specify data that are not available in all areas. All planning regions should, at a minimum, consider the recommended analyses using data sources listed under *Widely Available Data*. Sources of data that are widely available are census, vital statistics, AIDS surveillance, National HIV Survey of Childbearing Women, HIV screening of Job Corps entrants, HIV screening of civilian applicants for military service, surveillance of bacterial sexually transmitted diseases, and the Youth Risk Behavior Surveillance System. Though widely available, some data are not available at the local level. Data from HIV Counseling and Testing programs, the Behavioral Risk Factor Surveillance System, and other behavioral studies may be included in the epidemiologic profile but may be more valuable for evaluating services in the needs assessment.

All epidemiologic terms must be defined so persons on the planning group who do not have technical backgrounds can understand the profile. The profile should also discuss the relative value of different sources of data and provide a brief narrative of the strengths and limitations of data sources. Technical assistance with analyzing, interpreting and presenting epidemiologic data is available from CDC and the Council of State and Territorial Epidemiologists.

In many regions, data from certain analyses cannot be presented because of small numbers of HIV infections or AIDS cases. Reporting small numbers of cases may lead to a breach of confidentiality and to the inadvertent disclosure of a person's identity. Showing data with small numbers may be acceptable only if there is no risk of such inadvertent disclosure. Persons preparing epidemiologic profiles must know their state and local laws regarding confidentiality and data release to ensure that AIDS case data and HIV seroprevalence data included in the profile are in accordance with such laws.

Although several years of data in many areas may need to be aggregated to protect confidentiality, showing only cumulative totals of data from 1981 to the present should be avoided if possible. Data from early in the epidemic may not represent emerging HIV transmission patterns. Epidemiologists developing the profile should determine when aggregating data is appropriate and what aggregates are most useful. For example, creating 3-year groups of data from 1981 to the present may be appropriate for trend analyses.

There is no single best format for the epidemiologic profile. At a minimum, it should address the key questions and conclude with a list of priority populations for prevention services. An executive summary may be an effective method of communicating the key data in the profile.